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Bilingual problem-solving training for caregivers of adults with dementia: A randomized, factorial-design protocol for the CaDeS trial

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Abstract

Objective: Caregivers of individuals with Alzheimer's disease and related dementias (ADRD) often experience debilitating caregiver burden and emotional distress. To address these negative emotional consequences of caregiving, we will test and refine a strategy training intervention – Problem-Solving Training (PST) – that promotes self-efficacy and reduces caregiver burden and depressive symptoms. Previous research supports efficacy of PST; however, we do not know exactly how many PST sessions are needed or if post-training "boosters" are required to maintain PST benefits. Additionally, we translated and culturally-adapted PST into "Descubriendo Soluciones Juntos" (DSJ), our novel intervention for Spanish-speaking caregivers.

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Declaration of interests

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

Method: In this 2 × 2 factorial design randomized controlled trial, we will test remotely-delivered PST/DSJ sessions for both English- and Spanish-speaking caregivers of persons with ADRD to determine the optimal number of PST/DSJ sessions and ongoing "booster" sessions needed to best help caregivers navigate their current and future needs.

Aims: 1) Compare the efficacy of three vs. six PST/DSJ sessions each with and without booster sessions for decreasing caregiver burden and depression and enhancing caregiver problem-solving; **2)** Identify key factors associated with efficacy of PST/DSJ, including age, gender, primary language, relationship to care recipient, and uptake of the PST/DSJ strategy.

Results: These results will establish guidelines needed for an evidence-based, culturally-adapted, and implementable problem-solving intervention to reduce caregiver stress and burden and improve caregiver health and well-being.

Conclusion: This work promotes inclusion of diverse and underserved populations and advances therapeutic behavioral interventions that improve the lives of caregivers of individuals with chronic conditions.

Keywords

Caregiver; Dementia; Alzheimer's disease and related dementia; Problem-solving; Spanish language; Dementia care; Psychosocial intervention; Metacognitive strategies

1. Introduction

Nearly six million people in the United States (US) currently provide unpaid care to an individual with Alzheimer's disease or related dementias (ADRD) [1]. Alzheimer's disease (AD) represents 60–80% of all dementia cases and is characterized by irreversible, progressive memory loss and neurocognitive impairment that negatively affects independence in activities of daily living. [2] Disease duration can be 15–26 years, encompassing preclinical to severe phases, with much of that time requiring partial to complete assistance from others [3–7]. Vascular dementia is the second most common (15–20%) type, often coexisting with AD [8–10], and dementia with Lewy bodies is the third most prevalent (4–16% of all cases) [11–13]. ADRD are among the most expensive health conditions in the US, with the 2018 estimated lifetime care cost being USD350,173 [3].

Regardless of etiology, ADRD can be exceptionally burdensome to individuals with dementia and their families and caregivers. Caregivers of persons with ADRD often experience caregiver burden, depression, problematic alcohol use, health problems, isolation, and poor quality of life [14–19]. Caregiver burden is particularly concerning for the growing US Hispanic/Latino population, which is often underserved due to limited access to linguistically and culturally appropriate services [20]. Older Hispanic/Latino individuals are 1.5 times more likely to develop dementia than non-Hispanic Whites [2,21], and by 2060, the number of Hispanic older persons with ADRD may increase to 3.2 million [22].

Most caregiver interventions provide education to improve knowledge about ADRD and teach practical skills related to managing the medical needs and behaviors of care recipients [23–25]. However, interventions that focus on reducing caregiver stress may reverse the

negative impact of caregiver burden [26]. Therefore, there is a critical need to provide evidence-based strategies, including effective problem-solving skills, that help caregivers balance their personal lives and needs while managing their care recipients' chronic health conditions [25].

Problem-Solving Training (PST) is an evidence-based strategy training intervention that teaches a simple, systematic method for evaluating problems, generating and selecting solutions, developing specific goals and action plans, and evaluating and revising plans as needed [27–39]. PST reduces emotional distress and caregiver burden and promotes adaptive coping skills in caregivers of individuals with various disabilities, including dementia [28,30,33–36,40]. Our group translated and culturally adapted PST to "Descubriendo Soluciones Juntos" (DSJ) [41] to address the needs of Spanish-speaking caregivers. PST/DSJ is delivered remotely by telephone or videoconference, thus eliminating access barriers to caregiver self-care [29,42,43]. Given its demonstrated generalizability, we hypothesize that PST would decrease caregiver burden and depressive symptoms in caregivers of persons with ADRD. Furthermore, PST/DSJ has the potential to be incorporated across clinical settings into existing education-based caregiver interventions to fill current gaps in clinical practice. However, a paucity of data continues to impede implementation. To address this gap in knowledge, we propose the Caregivers in Dementia PST/DSJ (CaDeS) trial, a 2 × 2 factorial design randomized control optimization trial to test PST/DSJ the best combination of sessions and boosters for reducing caregiver burden and depressive symptoms and improving problem-solving skills among English- and Spanish-speaking caregivers of persons with ADRD and to determine individual differences that affect PST/DSJ efficacy.

2. Design and methods

2.1. Overview and design

This is a multi-site, 2 × 2 factorial design randomized control trial of three versus six sessions of PST/DSJ with or without (±) booster sessions for English- and Spanish-speaking caregivers of adults with ADRD. Our primary objective is to determine the optimal combination of PST sessions ± boosters that have the greatest effect on emotional symptoms and caregiver burden for caregivers. The secondary objective is to identify factors associated with individual differences in response to treatment. See Fig. 1 for the study design. We hypothesize that:

1. Six PST/DSJ sessions, compared to three sessions, will be optimal for improving depressive symptoms and caregiver burden, and secondarily problem-solving skills, of both English- and Spanish-speaking caregivers 6 months after baseline.
2. Monthly brief booster sessions, compared to no booster sessions, will be optimal for improving depressive symptoms and caregiver burden, and secondarily problem-solving skills, of both English- and Spanish-speaking caregivers 6 months after baseline.
3. Response to treatment will be associated with age, gender, and uptake of the PST/DSJ strategy.

2.2. Overview of the intervention

PST is a metacognitive strategy training approach, grounded in both problem-solving and self-management theory [44,45], that teaches a simple, systematic method for evaluating problems, generating and selecting solutions, developing specific goals and action plans, and evaluating and revising plans as needed (see Fig. 2 for the strategy steps and mnemonic in both English and Spanish) [33,46]. With the guidance of a therapist, caregivers learn to break down larger problems or goals into manageable and concrete steps. By solving problems that may have seemed overwhelming, they gain self-efficacy [33,34,44]. Though it follows a standardized protocol, PST/DSJ offers the flexibility to individualize sessions to the unique needs, values, and goals of the participant and teaches a global problem-solving strategy that can be applied to any problem the participant may select during the sessions or face in the future. All goals are self-selected by participants, maximizing the likelihood that participants will be engaged, motivated, and ready to address the chosen goals. Our team translated and culturally adapted PST to DSJ for Spanish-speaking Hispanic/Latino caregivers [41].

PST/DSJ sessions will be delivered by trained social workers using a specific curriculum validated in our previous research studies [33,34,41–43]. All intervention sessions will occur over the telephone or via Microsoft Teams. PST has been successfully delivered in-person and over the phone, with similar effects. In the first PST/DSJ session, regardless of allocation, participants receive education and community resources and orientation to study materials and the PST/DSJ strategy in their preferred language (English or Spanish).

The PST/DSJ intervention will consist of either three or six sessions (about 30–60 min each), depending on allocation, that follow a structured format described in the PST manual from our current Caregiver PST (CP-PST) intervention study [33]. See Table 1 for brief summary of the session content for three and six session conditions. We will aim to conduct one session per week. This timeframe will enable caregivers to put their plans into action between sessions.

In these sessions, the therapist will introduce the participant to the PST/DSJ steps and structured PST/DSJ Worksheets included in the participant folder, then help the caregiver generate and select a problem to address first. The interventionist then facilitates the caregiver's use of the ABCDEF steps of PST, or ABCDE steps of DSJ (see Fig. 2), using the PST/DSJ Worksheets to develop a specific action plan to solve the problem. The coherent Spanish translation for the key mnemonic ABCDEF combines the E and F steps into one broader E step to conserve all the concepts from the original text, resulting in ABCDE. [41] This sequence allows for maximal individual choice within a structure that is easy to remember. As problems are attempted or solved, the caregiver will learn how to perform the steps on his/her own, thus acquiring self-management problem-solving skills that will be applicable to future problems. The final session includes a review and generalization of the PST/DSJ steps and progress made and focuses on successful strategies and future application to new and unexpected problems that may arise. The advantage of this model is the mastery afforded by the success of relatively independent problem solving, which may improve self-efficacy and enable caregivers to become independent for future problem solving.

After completion of the intervention (treatment) sessions, participants allocated to a condition with booster sessions will receive monthly boosters until 6 months post-treatment. Booster sessions provide a refresher of the PST/DSJ strategy and a brief discussion of both how the caregiver has used the strategy since the last session and how they will use the strategy in the future.

2.3. Interventionist training

PST/DSJ therapists for this trial are licensed social workers; the DSJ therapist is a native Spanish-speaker. Therapists are trained and supervised by the study principal investigator, a certified rehabilitation counselor with expertise in problem-solving interventions, and one study co-investigator, a bilingual Latina rehabilitation neuropsychologist with expertise in delivering linguistically and culturally appropriate services. Training follows a standardized training protocol consisting of a therapist manual, didactic sessions, self-study, and iterative practice supervised by investigators. Therapists are also trained in the fidelity protocol (see below). Therapists complete annual training boosters, ongoing teleconference calls with the study team, and ongoing fidelity checks to ensure continuity of intervention delivery.

2.4. PST/DSJ fidelity assessment

We will monitor intervention fidelity according to our established fidelity protocol [33]. All sessions are audio/video recorded, and a random 10% of all delivered PST/DSJ sessions are assessed for fidelity to the intervention protocol. Fidelity assessment includes both adherence to the protocol and competence of the therapist's delivery. Whether or not the interventionist takes a facilitating or directive approach is considered when rating competence. A facilitative approach (high competence) demonstrates respect for the participant's individual strengths and ability to problem-solve independently, involves shared goal setting and decision-making, and has participants (rather than therapists) leading the process. By contrast, a directive approach (low competence) has therapists leading the process, making all decisions, and specifying goals, solutions, and tasks. A directive approach does not allow participants to set their own goals, develop their own plans, or make their own mistakes.

2.5. Participants

Participants will be English- and Spanish-speaking caregivers of persons with ADRD, recruited from clinical care sites, existing research recruitment databases, and caregiver registries at the University of Texas Southwestern Medical Center (coordinating site) or University of Texas Rio Grande Valley, through outreach and education events, community-organizations serving persons with ADRD and their caregivers, and advertisements through flyers and social media outlets. See Table 2 for inclusion/exclusion criteria for participants.

2.6. Assessment schedule and training

Participants will have the option to complete questionnaires entirely through the electronic REDCap™ database. Alternatively, trained research staff will collect responses to measures, as needed, via telephone at baseline, end of intervention, and 6-months post-intervention.

2.7. Randomization and allocation

Participants will be randomized to 1 of 4 treatment groups (3 vs. 6 sessions each with and without booster sessions) with equal probability. Randomization will be stratified by the two native languages and gender, which will then occur in blocks of 8. As a result, 2 participants will be allocated to each of the 4 conditions within each randomization block so that the four treatment groups will have the same allocation ratio [48]. Participants in each block speak the same native language and have the same gender. We will uniformly sample without replacement (i.e. equal probability) random numbers from a set containing two 1's, two 2's, two 3's, and two 4's to generate each randomization block in the randomization table. We will use REDCap™'s randomization feature to allocate participants once they have completed baseline assessments.

2.8. Outcomes measures

We will collect demographic data (age, gender, race, ethnicity, education), caregiver relationship information (nature, duration, living status, relationship quality), and outcome measurements (caregiver burden, depressive symptoms, problem-solving skills) via REDCap™ or over the telephone. See measures outlined in Table 3.

2.9. Translation of study materials

The following study materials were translated and adapted for Spanish speakers: DSJ participant packet, DSJ Interventionist Manual, Upstream Social Interaction Risk Scale (U-SIRS-13), Social Problem Solving Inventory Revised Short Form (SPSI-RS Scale), and Family Caregiver Scale (all other measures had a Spanish-language version already validated – see Table 2 for relevant validation studies). Measures were translated by Latin American native Spanish speaking members of the research team using a combination of back translation and verification process. Our team consists of Spanish-speakers with origins including Mexico, Puerto Rico, Venezuela, and Uruguay.

2.10. Sample size determination

Our pilot data [34] indicated that the improvement in depressive symptoms (PHQ-8 score) from baseline to 6-month follow-up was on average 6.5 with standard deviation 6.71, where the sample size was 16. Given this effect size, a sample size of 11 participants in a study arm can achieve 80% power at a significance level of 0.05 in a paired two-sided test to detect statistically significant improvement of the PHQ-8 score from baseline to 6-month follow-up in that arm. In the comparison of any two arms (for 3 vs. 6 sessions, and booster vs non-booster sessions), the sample size of 23 per arm can achieve 80% power at significance level 0.05 to detect the mean difference of 0.84 standard deviation. Furthermore, 10 out of the 16 participants (62.5%) in our pilot study had improvement greater than 3. Given that the pilot sample is a mixture of participants having different number of sessions, we conducted a sensitivity analysis assuming the proportion of improvement could be 30% to 60% in one arm. The sample size of 23 per arm can achieve 80% power at significance level 0.05 to detect the improvements between any two arms of 30% vs. 65%, 40% vs. 75%, 50% vs. 83%, and 60% vs. 90%. Accounting for 10% attrition, the required total sample size would be 104 (26 per arm) to achieve the same statistical power. As a result, the total sample

size of 208 (n = 26 per arm in English and n = 26 per arm in Spanish) ensures sufficient statistical power to test improvement in depressive symptoms (PHQ-8 scores). For other interventions that teach problem-solving skills to informal caregivers, similar effect sizes were noted for decreasing caregiver burden and improving problem-solving [28,49–51], suggesting that the required sample size would be similar to achieve the necessary power for these outcomes as well.

2.11. Statistical analysis plan

In the analysis of Aim 1, the two primary outcomes (i.e. depressive symptoms PHQ score and caregiver burden ZBI score) can both be treated as continuous measurements. Descriptive statistics of the outcomes, including mean, standard deviation, median, and interquartile range, will be reported at baseline, end of intervention, and six months post-intervention for all participants, by the four intervention arms, and by strata of gender and native language. Linear mixed-effects models with longitudinal measurements at baseline, end of intervention and post-intervention follow-up will be used to test the effect of three vs. six sessions, the effect of boosters vs. no boosters, and their interaction, treating the two strata (gender, language) as random effects. Subgroup analysis will also be conducted by gender and native language. Secondary outcomes, including caregiver problem-solving skills and positive aspects of caregiving, will be analyzed using the same approach.

Besides the longitudinal analysis, we will also model whether there is improvement from baseline to six months post-intervention as a binary outcome. Participants will rate their perceived improvement in mood and in feelings of caregiver strain at follow-up on a 5-level ordinal scale (much worse, worse, the same, better, much better). Using this 5-level ordinal scale of perceived change and following previously established guidelines [52], we will calculate Minimal Clinically Important Differences (MCID) for the PHQ and ZBI in our sample. We will then categorize participants as Improved or Not Improved using this MCID in each outcome. Improvement will be considered “yes” for depressive symptoms if their PHQ score decreases by the PHQ MCID value or more and “yes” for caregiver burden if their ZBI score decreases by the ZBI MCID or more. We will conduct mixed-effect ordered logistic regression models with subject-specific random effects to identify the optimal intervention group for the two primary outcomes. We will report the odds ratios and the corresponding p-values of three vs. six sessions and boosters vs. no boosters. Bayesian and Bayesian-frequentist hybrid inference [53–55] will be considered to run the mixed-effect logistic regression models. In accordance with the approach used to power the current study, a significant result for any of the treatment comparisons (i.e., three vs. six sessions, boosters vs. no boosters) will be defined as a posterior probability greater than 98.33% to achieve an overall experiment-wise significance level of 5%.

In the analysis of Aim 2, we will investigate covariates including age, gender, engagement in and uptake of PST, and goal attainment. We will categorize participants into one of three response to intervention groups: One, response group has PHQ scores decrease by the calculated MCID from baseline to six months. Two, no change group has PHQ scores remain within the MCID between baseline and six months. Three, decliner group has PHQ scores increase by the MCID or more at six months. We will examine predictors of

response to intervention group using multinomial logistic regression. Univariable analysis will test each covariate adjusting for gender, native language, three vs. six sessions, and the presence of boosters. Multivariable analysis will include multiple covariates and test their statistical significance. Multicollinearity issues will be assessed by variance inflation factor and correlation matrix of the parameter estimates (e.g. SAS software, procedure logistic, "corrb" command). If the multicollinearity is significant, variable dimension reduction procedures such as principal component analysis will be implemented to reduce the number of independent variables. We will also explore predictors of change in the primary and secondary outcomes as continuous scores from baseline to six-months post-intervention to account for magnitude of changes. Univariable and multivariable linear mixed-effects models will be used to test the covariates. We will apply the same method to analyze response to treatment for caregiver burden. A p-value of less or equal to 0.05 will be deemed statistically significant in this analysis, and all tests will be two-sided. We will use intention-to-treat analysis and implement appropriate missing value imputation methods as needed and appropriate.

2.12. Ethics

UT Southwestern Medical Center's Institutional Review Board (IRB) will serve as the central IRB for the study. IRB approval will be obtained prior to recruitment. Documented informed consent will be obtained from all participants. Further, we have established protocols for managing any crises that may arise in the context of intervention delivery (e. g. a participant endorsing suicidal ideation). This trial is registered to ClinicalTrials.gov Identifier: NCT04748666.

3. Discussion

As demographics shift due to the rapid growth of the aging population in the US, and absent meaningful disease-modifying interventions, ADRD will continue to create a significant financial burden on health care delivery systems, families, and society at large. Persons with ADRD require increasing levels of care and support as their disease progresses, including medical treatment, prescriptions, medical equipment, home safety modifications, safety services, personal care, adult day care, and, ultimately, full-time residential services [56]. Expenses related to the medical care of persons with dementia are estimated at $305 billion in 2020, with Medicare or Medicaid covering about 67% of costs related to total health care and long-term care [2,57]. In 2019 alone, there were approximately 18.6 billion hours of unpaid care provided to persons with dementia, with an estimated value of $244 billion [2,58,59]. Thus, the ongoing contribution of caregivers and informal caregiving to the health and well-being of persons with ADRD is vital and will likely expand.

Caregiver burden is a complex, multidimensional response to physical, psychological, social, and financial stressors associated with caregiving [60,61]. Recent studies, meta-analyses, and systematic reviews have reported that the prevalence of depression is higher among ADRD caregivers (30–40%) compared to caregivers of those with stroke or schizophrenia [62–64]. ADRD caregivers also report higher appraisals of stress and burden compared to caregivers of stroke patients [65]. Furthermore, there is emerging evidence that caregiver

distress has a direct impact on the health and well-being of care recipients [66]. A prospective cohort study of community-dwelling older adults and their caregivers revealed that recipients with caregivers that had a baseline ZBI score in the highest quartile were 1.54 and 1.51 times more likely to show increased risk of all-cause mortality and hospitalization during a three-year follow-up, respectively, compared to those with caregivers in the lowest ZBI score quartile [67]. In another study with 139 Hispanic family caregivers, higher caregiver burden was associated with lower satisfaction with social networks and higher ADRD severity [68]. Caregiver burden has been identified as a predictor of institutionalization of persons with ADRD [69,70] and can exacerbate care recipient behavioral and psychological symptoms and increase likelihood of care recipient abuse [66]. Effective caregiver interventions that alleviate perceived burden and psychological distress could mitigate detrimental health outcomes of both caregivers and ADRD care recipients.

What are the important characteristics of a robust caregiver intervention? A meta-analysis of 30 studies on psychosocial interventions for ADRD caregivers found that key characteristics of effective interventions are the involvement of their care recipient, addressing issues relating to caring for their care recipients, occurring in a structured program, and teaching caregivers problem-solving skills to manage and balance the care of their care recipient and their own self-care [71]. A recent review of family caregiver interventions, including seven meta-analyses and 17 systematic reviews of randomized controlled trials, identified several aspects of effective interventions that were more likely to improve caregiver burden. These aspects included active involvement of caregivers in the intervention, rather than caregivers just passively receiving information, and tailored, flexible interventions that met the changing needs of caregivers during the course of a care recipients' ADRD [72]. However, current caregiver interventions focus predominantly on caregiving skills and disease-specific education [23], rarely including problem-solving skills training to help caregivers translate knowledge into meaningful action [73,74]. Interventions that focus on psychosocial needs, educational needs, case management, and emotional support have been reported to effectively promote self-management for caregivers [23,74,75], but most are resource intensive requiring long hours of commitment or require physical attendance that can be challenging for caregivers [23,73–75]. Thus, there is a critical need to provide evidence-based problem-solving skills training to caregivers through a structured, customizable, adaptable program that requires limited time and resources so that caregiver can better manage their own lives and their care recipients' chronic health demands.

Informal or family caregivers of persons with ADRD represent a diverse and often underserved population. They are typically women (67%), over half are children or in-laws of care recipients, 33% are African American, Hispanic/Latino, Asian, or of mixed race or ethnic heritage, and approximately 25% are of the "sandwich generation" where they are caring for both parents and children [2,60,76,77]. Hispanic/Latino caregivers have additional challenges and risk factors to navigate with their care recipients, including language barriers, often low socioeconomic status, comorbidities related to vascular issues associated with dementia [78–80], higher rates of diabetes, stroke, and hypertension [81,82], lower education levels [83], and immigrant status [84]. Of great interest to our group, Hispanic/Latinos make up approximately 39.7% of the population in Texas and 18.4% of the US [85]. As the aging Hispanic/Latino population grows, constituting 20% of the nation's

seniors by 2050 [86], with an increasing number developing dementia [22], the demand for support for their caregivers will follow. However, studies of caregiver interventions typically exclude Spanish-speaking participants [18]. Contributing factors include a lack of evidence-based, translated, culturally sensitive and culturally-adapted interventions [87]. A recent randomized control trial of "Circulo de Cuidado" (Circle of Care), a Spanish language, culturally sensitive, targeted cognitive behavioral (CBT) group intervention vs. psychoeducational intervention for Latino caregivers demonstrated that CBT participants reported lower neuropsychiatric symptoms in their care recipient, less caregiver distress, improved caregiver self-efficacy, and less severe depressive symptoms over time [88]. Data from a secondary analysis of the Resources for Enhancing Alzheimer's Caregiver Health (REACH) II study, a multisite randomized trial of multicomponent caregiver interventions, suggested that Latinos who were more acculturated benefited more from the intervention [89]. Our team translated and adapted PST to DSJ, a personalized problem-solving skills training intervention for Hispanic/Latino caregivers of individuals with traumatic brain injury [41]. PST was uniquely suited for cultural adaptation for several reasons. First, problem-solving strategies have previously been incorporated into health interventions for specific Spanish-speaking subculture groups. Second, PST/DSJ considers the inclusion of loved ones in the recovery process and supports a holistic approach that validates both cultural values of *respeto*, *familismo* and religious values. Finally, PST/DSJ is highly flexible, thus able to adapt to an individual's needs and values, as well as the diverse cultural needs and values of the broader Hispanic/Latino community [41]. These types of interventions have the potential to mitigate the disparities that exist along health care delivery and access.

Here we describe a 2 × 2 factorial design randomized clinical trial of PST/DSJ for caregivers of persons with ADRD, to determine the optimal "dose" or combination of PST/DSJ sessions ± boosters delivered remotely over the telephone or videoconference. At the completion of this study, we will have determined the most effective mix of regular sessions and boosters for most caregivers and the extent to which PST/DSJ needs to be customized to be most efficacious for every individual. We will also have identified the important factors associated with response to treatment, such as age, gender, and engagement in and uptake of PST/DSJ. This study will address existing gaps in knowledge and provide a means to overcome barriers that prevent widespread implementation of caregiver interventions for English- and Spanish-speakers, including limited resources, time investment, language differences, and culture. The incorporation of PST/DSJ across clinical settings into existing education-based interventions will fill current gaps in clinical practice, and implementation of PST/DSJ in community-based settings will address healthcare inequities across the US.

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References

[1]. Brookmeyer R, Abdalla N, Kawas CH, Corrada MM, Forecasting the prevalence of preclinical and clinical Alzheimer's disease in the United States, Alzheimers Dement J. Alzheimers Assoc14 (2) (2018 2) 121–129.

[2]. Alzheimer"s Association, Alzheimer's disease facts and figures, Alzheimers Dement J. Alzheimers Assoc2020 (2020) 16(3).

[3]. Vermunt L, Sikkes SAM, van den Hout A, Handels R, Bos I, van der Flier WM, et al., Duration of preclinical, prodromal and dementia Alzheimer disease stages in relation to age, sex, and APOE genotype, Alzheimers Dement J. Alzheimers Assoc15 (7) (2019 7) 888–898.

[4]. Sperling RA, Aisen PS, Beckett LA, Bennett DA, Craft S, Fagan AM, et al., Toward defining the preclinical stages of Alzheimer's disease: recommendations from the National Institute on Aging-Alzheimer's Association workgroups on diagnostic guidelines for Alzheimer's disease, Alzheimers Dement J. Alzheimers Assoc7 (3) (2011 5) 280–292.

[5]. Albert MS, DeKosky ST, Dickson D, Dubois B, Feldman HH, Fox NC, et al., The diagnosis of mild cognitive impairment due to Alzheimer's disease: recommendations from the National Institute on Aging-Alzheimer's Association workgroups on diagnostic guidelines for Alzheimer's disease, Alzheimers Dement J. Alzheimers Assoc7 (3) (2011 5) 270–279.

[6]. Lim YY, Kalinowski P, Pietrzak RH, Laws SM, Burnham SC, Ames D, et al., Association of β-amyloid and apolipoprotein E ε4 with memory decline in preclinical Alzheimer disease, JAMA Neurol. 75 (4) (2018 4 1) 488–494. [PubMed: 29356823]

[7]. Farias ST, Mungas D, Reed BR, Harvey D, DeCarli C, Progression of mild cognitive impairment to dementia in clinic- vs community-based cohorts, Arch. Neurol66 (9) (2009 9) 1151–1157. [PubMed: 19752306]

[8]. Kua EH, Ho E, Tan HH, Tsoi C, Thng C, Mahendran R, The natural history of dementia, Psychogeriatr. Off. J. Jpn. Psychogeriatr. Soc14 (3) (2014 9) 196–201.

[9]. Staekenborg SS, Pijnenburg YAL, Lemstra AW, Scheltens P, Vd Flier WM, Dementia and rapid mortality: who is at risk?J. Alzheimers Dis53 (1) (2016 4 19) 135–142. [PubMed: 27104894]

[10]. Kim JH, Go SM, Seo SW, Kim SH, Chin J, Moon SY, et al., Survival in subcortical vascular dementia: predictors and comparison to probable Alzheimer's disease in a tertiary memory clinic population, Dement. Geriatr. Cogn. Disord40 (3–4) (2015) 210–221. [PubMed: 26227072]

[11]. Mueller C, Ballard C, Corbett A, Aarsland D, The prognosis of dementia with Lewy bodies, Lancet Neurol. 16 (5) (2017 5 1) 390–398. [PubMed: 28342649]

[12]. Long-Term Mortality in a Cohort of Home-Dwelling Elderly with Mild Alzheimer's Disease and Lewy Body Dementia - PubMed [Internet] [cited 2021 Mar 15]. Available from: https://pubmed.ncbi.nlm.nih.gov/24732348/, 2021.

[13]. Vann Jones SA, O'Brien JT, The prevalence and incidence of dementia with Lewy bodies: a systematic review of population and clinical studies, Psychol. Med44 (4) (2014 3) 673–683. [PubMed: 23521899]

[14]. Wolff JL, Spillman BC, Freedman VA, Kasper JD, A national profile of family and unpaid caregivers who assist older adults with health care activities, JAMA Intern. Med176 (3) (2016 3) 372–379. [PubMed: 26882031]

[15]. Rospenda KM, Minich LM, Milner LA, Richman JA, Caregiver burden and alcohol use in a community sample, J. Addict. Dis29 (3) (2010 7) 314–324. [PubMed: 20635281]

[16]. Sörensen S, Duberstein P, Gill D, Pinquart M, Dementia care: mental health effects, intervention strategies, and clinical implications, Lancet Neurol. 5 (11) (2006 11) 961–973. [PubMed: 17052663]

[17]. Vitaliano PP, Zhang J, Scanlan JM, Is caregiving hazardous to one's physical health? A meta-analysis, Psychol. Bull129 (6) (2003 11) 946–972. [PubMed: 14599289]

[18]. Napoles AM, Chadiha L, Eversley R, Moreno-John G, Reviews: developing culturally sensitive dementia caregiver interventions: are we there yet?Am. J. Alzheimers Dis. Other Dement25 (5) (2010 8) 389–406.

[19]. Arango Lasprilla JC, Moreno A, Rogers H, Francis K, The effect of dementia patient's physical, cognitive, and emotional/ behavioral problems on caregiver well-being: findings from a Spanish-speaking sample from Colombia, South America, Am. J. Alzheimers Dis. Other Dement24 (5) (2009 11) 384–395.

[20]. Hispanic/Latino - The Office of Minority Health [Internet] [cited 2021 Mar 24]. Available from: https://minorityhealth.hhs.gov/omh/browse.aspx?lvl=3&lvlid=64, 2021.

[21]. Mehta KM, Yeo GW, Systematic review of dementia prevalence and incidence in United States race/ethnic populations, Alzheimers Dement J. Alzheimers Assoc13 (1) (2017 1) 72–83.

[22]. Racial and Ethnic Estimates of Alzheimer's Disease and Related Dementias in the United States (2015–2060) in Adults Aged ≥65 Years - Matthews - 2019 -Alzheimer's & Dementia - Wiley Online Library [Internet] [cited 2021 Feb 4]. Available from: https://alz-journals.onlinelibrary.wiley.com/doi/full/10.1016/j.jalz.2018.06.3063, 2021.

[23]. Parker D, Mills S, Abbey J, Effectiveness of interventions that assist caregivers to support people with dementia living in the community: a systematic review, Int. J. Evid. Based Healthc6 (2) (2008 6) 137–172. [PubMed: 21631819]

[24]. Schulz R, Burgio L, Burns R, Eisdorfer C, Gallagher-Thompson D, Gitlin LN, et al., Resources for enhancing Alzheimer's caregiver health (REACH): overview, site-specific outcomes, and future directions, The Gerontologist43 (4) (2003 8) 514–520. [PubMed: 12937330]

[25]. Prince M, Guerchet M, Prina M, Alzhiemer's Disease International. Policy Brief for Heads of Government: The Global Impact of Dementia 2013–2050 [Internet]. London, 12. Available from: https://www.alzint.org/u/2020/08/GlobalImpactDementia2013.pdf, 2013.

[26]. Allen AP, Curran EA, Duggan Á, Cryan JF, Chorcoráin AN, Dinan TG, et al., A systematic review of the psychobiological burden of informal caregiving for patients with dementia: focus on cognitive and biological markers of chronic stress, Neurosci. Biobehav. Rev73 (2017 2) 123–164. [PubMed: 27986469]

[27]. Rivera PA, Elliott TR, Berry JW, Grant JS, Problem-solving training for family caregivers of persons with traumatic brain injuries: a randomized controlled trial, Arch. Phys. Med. Rehabil89 (5) (2008 5) 931–941. [PubMed: 18452743]

[28]. Powell JM, Fraser R, Brockway JA, Temkin N, Bell KR, A telehealth approach to caregiver self-management following traumatic brain injury: a randomized controlled trial, J. Head Trauma Rehabil31 (3) (2016 6) 180–190. [PubMed: 26394294]

[29]. Pfeiffer K, Beische D, Hautzinger M, Berry JW, Wengert J, Hoffrichter R, et al., Telephone-based problem-solving intervention for family caregivers of stroke survivors: a randomized controlled trial, J. Consult. Clin. Psychol82 (4) (2014 8) 628–643. [PubMed: 24911421]

[30]. Elliott TR, Berry JW, Grant JS, Problem-solving training for family caregivers of women with disabilities: a randomized clinical trial, Behav. Res. Ther47 (7) (2009 7) 548–558. [PubMed: 19361781]

[31]. Elliott TR, Berry JW, Brief problem-solving training for family caregivers of persons with recent-onset spinal cord injuries: a randomized controlled trial, J. Clin. Psychol65 (4) (2009 4) 406–422. [PubMed: 19229946]

[32]. Elliott TR, Shewchuk RM, Richards JS, Family caregiver social problem-solving abilities and adjustment during the inital year of the caregiving role, J. Couns. Psychol48 (2) (2001) 223–232.

[33]. Juengst SB, Silva V, Goldin Y, Cicerone K, Lengenfelder J, Chiaravalloti N, et al., Care partner problem solving training (CP-PST) for care partners of adults with traumatic brain injury during inpatient rehabilitation: study protocol for a multisite, randomized, single-blind clinical feasibility trial, Contemp. Clin. Trials80 (2019 5) 9–15. [PubMed: 30885800]

[34]. Juengst SB, Osborne CL, Holavanahalli R, Silva V, Kew CL, Nabasny A, et al., Feasibility study of problem-solving training for care partners of adults with traumatic brain injury, spinal cord injury, burn injury, or stroke during the inpatient hospital stay, Arch. Rehabil. Res. Clin. Transl1 (3) (2019 12 1) 100009. [PubMed: 33543049]

[35]. Garand L, Morse JQ, Rebecca Chia L., Barnes J, Dadebo V, Lopez OL, et al., Problem solving therapy reduces subjective burden levels in caregivers of family members with mild cognitive impairment or early-stage dementia: secondary analysis of a randomized clinical trial, Int. J. Geriatr. Psychiatry34 (7) (2019 7) 957–965. [PubMed: 30868641]

[36]. Chiu M, Pauley T, Wesson V, Pushpakumar D, Sadavoy J, Evaluation of a problem-solving (PS) techniques-based intervention for informal carers of patients with dementia receiving in-home care, Int. Psychogeriatr27 (6) (2015 6) 937–948. [PubMed: 25615434]

[37]. Domingues NS, Verreault P, Hudon C, Reducing burden for caregivers of older adults with mild cognitive impairment: a systematic review, Am. J. Alzheimers Dis. Other Dement33 (7) (2018 11) 401–414.

[38]. Beinart N, Weinman J, Wade D, Brady R, Caregiver burden and psychoeducational interventions in Alzheimer's disease: a review, Dement. Geriatr. Cogn. Disord. Extra2 (1) (2012 1) 638–648.

[39]. McPherson KM, Kayes N, Weatherall M, Members of the Goals-SR Research Group, A pilot study of self-regulation informed goal setting in people with traumatic brain injury, Clin. Rehabil23 (4) (2009 4) 296–309. [PubMed: 19293290]

[40]. Baker A, Barker S, Sampson A, Martin C, Caregiver outcomes and interventions: a systematic scoping review of the traumatic brain injury and spinal cord injury literature, Clin. Rehabil31 (1) (2017 1) 45–60. [PubMed: 27009058]

[41]. Vega M, Nabasny A, Juengst SB, "Descubriendo Soluciones Juntos"—An argument for adapting problem-solving training for Latinx care partners after traumatic brain injury (TBI), Rehabil. Psychol65 (4) (2020) 337–346, 10.1037/rep0000310.

[42]. Brockway JA, St De Lore J, Fann JR, Hart T, Hurst S, Fey-Hinckley S, et al., Telephone-delivered problem-solving training after mild traumatic brain injury: qualitative analysis of service members' perceptions, Rehabil. Psychol61 (3) (2016 8) 221–230. [PubMed: 26797117]

[43]. Bell KR, Fann JR, Brockway JA, Cole WR, Bush NE, Dikmen S, et al., Telephone problem solving for service members with mild traumatic brain injury: a randomized, Clin. Trial. J. Neurotrauma34 (2) (2017 1 15) 313–321.

[44]. D'Zurilla TJ, Nezu AM, Maydeu-Olivares A, Social problem solving: theory and assessment, in: Social Problem Solving: Theory, Research, and Training, American Psychological Association, 2004, pp. 11–27.

[45]. Lorig KR, Holman H, Self-management education: history, definition, outcomes, and mechanisms, Ann. Behav. Med. Publ. Soc. Behav. Med26 (1) (2003 8) 1–7.

[46]. Nezu AM, Nezu CM, D'Zurilla TJ, Solving life's Problems, Springer, New York, NY, 2007.

[47]. Goal Attainment Scaling in Rehabilitation: Neuropsychological Rehabilitation: Vol 9, No 3–4 [Internet], 2021, 10.1080/096020199389365 [cited 2021 Feb 4]. Available from:.

[48]. Clinical Trials: A Methodologic Perspective, 3rd Edition | Wiley [Internet], Wiley.com. [cited 2021 Feb 17]. Available from: https://www.wiley.com/en-us/Clinical+Trials%3A+A+Methodologic+Perspective%2C+3rd+Edition-p-9781118959206, 2021.

[49]. Walter E, Pinquart M, How effective are dementia caregiver interventions? An updated comprehensive meta-analysis, The Gerontologist60 (8) (2020 11 23) 609–619. [PubMed: 33226434]

[50]. Cheng S-T, Zhang F, A comprehensive meta-review of systematic reviews and meta-analyses on nonpharmacological interventions for informal dementia caregivers, BMC Geriatr. 20 (1) (2020 4 15) 137.

[51]. Cheng HY, Chair SY, Chau JP-C, The effectiveness of psychosocial interventions for stroke family caregivers and stroke survivors: a systematic review and meta-analysis, Patient Educ. Couns95 (1) (2014 4 1) 30–44. [PubMed: 24485756]

[52]. Malec JF, Ketchum JM, A standard method for determining the minimal clinically important difference for rehabilitation measures, Arch. Phys. Med. Rehabil101 (6) (2020 6) 1090–1094. [PubMed: 31953077]

[53]. Yuan A, Bayesian frequentist hybrid inference, Ann. Stat37 (5A) (2009 10) 2458–2501.

[54]. Han G, Huang Y, Yuan A, Bayesian-frequentist hybrid approach for skew-normal nonlinear mixed-effects joint models in the presence of covariates measured with errors, Stat. Interface11 (2) (2018) 223–236.

[55]. Han G, Huang Y, Li Q, Chen L, Zhang X, Hybrid Bayesian inference on HIV viral dynamic models, J. Appl. Stat40 (11) (2013 11 1) 2516–2532.

[56]. Deb A, Thornton JD, Sambamoorthi U, Innes K, Direct and indirect cost of managing alzheimer's disease and related dementias in the United States, Expert. Rev. Pharmacoecon Outcomes Res17 (2) (2017 3 4) 189–202. [PubMed: 28351177]

[57]. National Alliance for Caregiviing N, American Association of Retired Persons A, Caregiving in the U.S. 2020 [Internet], 5. Available from, https://www.caregiving.org/wp-content/uploads/2021/01/full-report-caregiving-in-the-united-states-01-21.pdf, 2020.

[58]. Arno PS, Levine C, Memmott MM, The economic value of informal caregiving, Health Aff. (Millwood). 18 (2) (1999 3 1) 182–188.

[59]. U.S. Department of Labor, Bureau of Labor Statistics, Employment, Hours, and Earnings from the Current Employment Statistics Survey. [Internet] (10-CEU 6562160008, Home Health Care Services (NAICS code 6216),Average Hourly Earnings, July 2018.). Available from, www.bls.gov/ces/data.htm, 2018.

[60]. Isik AT, Soysal P, Solmi M, Veronese N, Bidirectional relationship between caregiver burden and neuropsychiatric symptoms in patients with Alzheimer's disease: a narrative review, Int. J. Geriatr. Psychiatry34 (9) (2019 9) 1326–1334. [PubMed: 30198597]

[61]. Dunkin JJ, Anderson-Hanley C, Dementia caregiver burden: A review of the literature and guidelines for assessment and intervention, Neurology51 (Issue 1, Supplement 1) (1998) S53–S60. 7 1.

[62]. Sallim AB, Sayampanathan AA, Cuttilan A, Ho R, Prevalence of mental health disorders among caregivers of patients with Alzheimer disease, J. Am. Med. Dir. Assoc16 (12) (2015 12) 1034–1041. [PubMed: 26593303]

[63]. Thunyadee C, Sitthimongkol Y, Sangon S, Chai-Aroon T, Hegadoren KM, Predictors of depressive symptoms and physical health in caregivers of individuals with schizophrenia, Nurs. Health Sci17 (4) (2015 12) 412–419. [PubMed: 26081195]

[64]. Collins RN, Kishita N, Prevalence of depression and burden among informal care-givers of people with dementia: a meta-analysis, Ageing Soc40 (11) (2020 11) 2355–2392.

[65]. Sheehan OC, Haley WE, Howard VJ, Huang J, Rhodes JD, Roth DL, Stress, burden, and well-being in dementia and non-dementia caregivers: insights from the caregiving transitions study, The Gerontologist 20 (2020 8).

[66]. Stall NM, Kim SJ, Hardacre KA, Shah PS, Straus SE, Bronskill SE, et al., Association of informal caregiver distress with health outcomes of community-dwelling dementia care recipients: a systematic review, J. Am. Geriatr. Soc67 (3) (2019 3) 609–617. [PubMed: 30536383]

[67]. Kuzuya M, Enoki H, Hasegawa J, Izawa S, Hirakawa Y, Shimokata H, et al., Impact of caregiver burden on adverse health outcomes in community-dwelling dependent older care recipients, Am. J. Geriatr. Psychiatry19 (4) (2011 4 1) 382–391. [PubMed: 20808120]

[68]. Luchsinger JA, Tipiani D, Torres-Patiño G, Silver S, Eimicke JP, Ramirez M, et al., Characteristics and mental health of Hispanic dementia caregivers in new York City, Am. J. Alzheimers Dis. Other Dement30 (6) (2015 9) 584–590.

[69]. Toot S, Swinson T, Devine M, Challis D, Orrell M, Causes of nursing home placement for older people with dementia: a systematic review and meta-analysis, Int. Psychogeriatr29 (2016 11 3) 1–14. [PubMed: 27890032]

[70]. Stephan A, Afram B, Koskenniemi J, Verbeek H, Soto ME, Bleijlevens MHC, et al., Older persons with dementia at risk for institutionalization in eight European countries: a cross-sectional study on the perceptions of informal caregivers and healthcare professionals, J. Adv. Nurs71 (6) (2015 6) 1392–1404. [PubMed: 25091706]

[71]. Brodaty H, Green A, Koschera A, Meta-analysis of psychosocial interventions for caregivers of people with dementia, J. Am. Geriatr. Soc51 (5) (2003 5) 657–664. [PubMed: 12752841]

[72]. Gitlin LN, Hodgson N, Caregivers as therapeutic agents in dementia care: The context of caregiving and the evidence base for interventions, in: Family Caregiving in the New Normal, Elsevier Academic Press, San Diego, CA, US, 2015, pp. 305–353.

[73]. Cheng S-T, Au A, Losada A, Thompson LW, Gallagher-Thompson D, Psychological interventions for dementia caregivers: what we have achieved, what we have learned, Curr. Psychiatry Rep21 (7) (2019 7) 59.

[74]. Jensen M, Agbata IN, Canavan M, McCarthy G, Effectiveness of educational interventions for informal caregivers of individuals with dementia residing in the community: systematic review and meta-analysis of randomised controlled trials: dementia caregiver education: systematic review and meta-analysis, Int. J. Geriatr. Psychiatry30 (2) (2015 2) 130–143. [PubMed: 25354132]

[75]. Leung P, Orrell M, Orgeta V, Social support group interventions in people with dementia and mild cognitive impairment: a systematic review of the literature: social support groups in dementia, Int. J. Geriatr. Psychiatry30 (1) (2015 1) 1–9. [PubMed: 24990344]

[76]. Fisher GG, Franks MM, Plassman BL, Brown SL, Potter GG, Llewellyn D, et al., Caring for individuals with dementia and cognitive impairment, not dementia: findings from the aging, demographics, and memory study, J. Am. Geriatr. Soc59 (3) (2011 3) 488–494. [PubMed: 21391939]

[77]. The Disproportionate Impact Of Dementia On Family And Unpaid Caregiving To Older Adults | Health Affairs [Internet], 2021, 10.1377/hlthaff.2015.0536 [cited 2021 Feb 16]. Available from:.

[78]. Yaffe K, Haan M, Blackwell T, Cherkasova E, Whitmer RA, West N, Metabolic syndrome and cognitive decline in elderly Latinos: findings from the Sacramento area Latino study of aging study, J. Am. Geriatr. Soc55 (5) (2007) 758–762. [PubMed: 17493197]

[79]. Filshtein TJ, Dugger BN, Jin L-W, Olichney JM, Farias ST, Carvajal-Carmona L, et al., Neuropathological diagnoses of demented Hispanic, black, and non-Hispanic white decedents seen at an Alzheimer's disease center, J. Alzheimers Dis68 (1) (2019 1 1) 145–158. [PubMed: 30775996]

[80]. Melgarejo JD, Aguirre-Acevedo DC, Gaona C, Chavez CA, Calmón GE, Silva ER, et al., Nighttime blood pressure interacts with APOE genotype to increase the risk of incident dementia of the Alzheimer's type in Hispanics, J. Alzheimers Dis77 (2) (2020) 569–579. [PubMed: 32675415]

[81]. Haan MN, Mungas DM, Gonzalez HM, Ortiz TA, Acharya A, Jagust WJ, Prevalence of dementia in older latinos: the influence of type 2 diabetes mellitus, stroke and genetic factors, J. Am. Geriatr. Soc51 (2) (2003 2) 169–177. [PubMed: 12558712]

[82]. Thomas IC, Allison MA, Hypertension in Hispanics/Latinos: epidemiology and considerations for management, Curr. Hypertens. Rep21 (6) (2019 4 25) 43.

[83]. Rodriguez FS, Aranda MP, Lloyd DA, Vega WA, Racial and ethnic disparities in dementia risk among individuals with low education, Am. J. Geriatr. Psychiatry26 (9) (2018 9 1) 966–976. [PubMed: 30005921]

[84]. Moon H, Badana ANS, Hwang S-Y, Sears JS, Haley WE, Dementia prevalence in older adults: variation by race/ethnicity and immigrant status, Am. J. Geriatr. Psychiatry27 (3) (2019 3) 241–250. [PubMed: 30573327]

[85]. United States Census Bureau [Internet], Available from, https://data.census.gov/cedsci/profile?q=United%20States&g=0100000US, 2019.

[86]. Federal Interagency Forum on Aging-Related Statistics, Older Americans 2012: Key Indicators of Well-Being [Internet] [cited 2012 Jul 2]. Available from: http://www.agingstats.gov/main_site/default.aspx, 2012.

[87]. Interventions for Hispanic Caregivers of Patients with Dementia: A Review of the Literature - Sarah M. Llanque, Maithe Enriquez [Internet]. [cited2021 Feb 4]. Available from: https://journals.sagepub.com/doi/10.1177/1533317512439794?url_ver=Z39.88-2003&rfr_id=ori:rid:crossref.org&rfr_dat=cr_pub%20%200pubmed, 2012.

[88]. Gonyea JG, López LM, Velásquez EH, The effectiveness of a culturally sensitive cognitive behavioral group intervention for Latino Alzheimer's caregivers, The Gerontologist56 (2) (2016 4) 292–302. [PubMed: 24855313]

[89]. Meyer OL, Liu XL, Tancredi D, Ramirez AS, Schulz R, Hinton L, Acculturation level and caregiver outcomes from a randomized intervention trial to enhance caregivers' health: evidence from REACH II, Aging Ment. Health22 (6) (2018 6) 730–737. [PubMed: 28436694]

[90]. Kroenke K, Spitzer RL, Williams JB, The PHQ-9: validity of a brief depression severity measure, J. Gen. Intern. Med16 (9) (2001 9) 606–613. [PubMed: 11556941]

[91]. Wulsin L, Somoza E, Heck J, The feasibility of using the Spanish PHQ-9 to screen for depression in primary care in Honduras, Prim. Care Companion J. Clin. Psychiatry4 (5) (2002 10) 191–195. [PubMed: 15014707]

[92]. Donders J, Darland K, Psychometric properties and correlates of the PHQ-2 and PHQ-9 after traumatic brain injury, Brain Inj. 31 (13–14) (2017) 1871–1875.

[93]. Pagán-Torres OM, Gonźalez-Rivera JA, Rosario-Hernández E, Psychometric analysis and factor structure of the Spanish version of the eight-item patient health questionnaire in a general sample of Puerto Rican adults, Hisp. J. Behav. Sci42 (3) (2020 8 1) 401–415.

[94]. Hébert R, Bravo G, Préville M, Reliability, validity and reference values of the Zarit burden interview for assessing informal caregivers of community-dwelling older persons with dementia*, Can. J. Aging Rev. Can. Vieil19 (4) (2000 1) 494–507.

[95]. Martín Carrasco M, Salvadó I, Nadal Álava S, Miji LC, Rico JM, Lanz P, et al., Adaptación para nuestro medio de la escala de sobrecarga del cuidador (Caregiver Burden Interview) de Zarit, Rev. Gerontol6 (4) (1996) 338–345.

[96]. Attkisson CC, Greenfield TK, The UCSF client satisfaction scales: I. The client satisfaction questionnaire-8, in: The Use of Psychological Testing for Treatment Planning and Outcomes Assessment, 2nd ed., Lawrence Erlbaum Associates Publishers, Mahwah, NJ, US, 1999, pp. 1333–1346.

[97]. Roberts RE, Atrkisson CC, Mendias RM, Assessing the client satisfaction questionnaire in English and Spanish, Hisp. J. Behav. Sci6 (4) (1984 12 1) 385–396.

[98]. Tarlow BJ, Wisniewski SR, Belle SH, Rubert M, Ory MG, Gallagher-Thompson D, Positive aspects of caregiving: contributions of the REACH project to the development of new measures for Alzheimer's caregiving, Res. Aging26 (4) (2004) 429–453.

[99]. Smith ML, Steinman LE, Casey EA, Combatting Social Isolation Among Older Adults in a Time of Physical Distancing: The COVID-19 Social Connectivity Paradox. Front Public Health [Internet], 721 [cited 2021 Mar 24];8. Available from: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7396644/, 2020.

[100]. D'Zurilla TJ, Nezu AM, Maydeu-Olivares A, Social Problem-Solving Inventory-Revised (SPSI-R): Manual, North Tonawanda, NY, Multi-Health Systems, 2002.

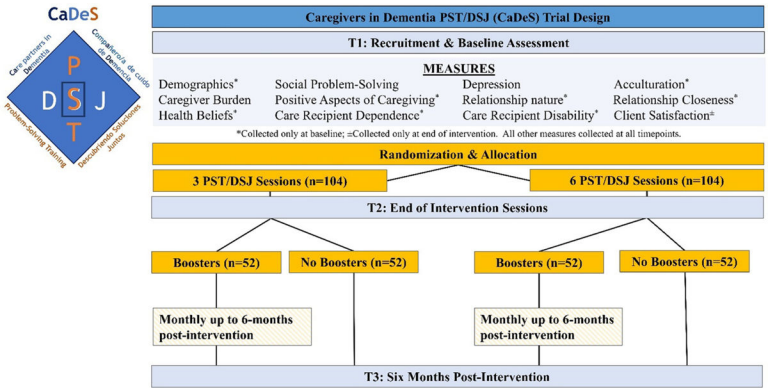

Fig. 1.

Caregivers in dementia PST/DSJ (CaDeS) Trial design.

PST: problem-solving training, DSJ: descubriendo soluciones juntos, T1: time 1, T2: time 2, T3: time 3.

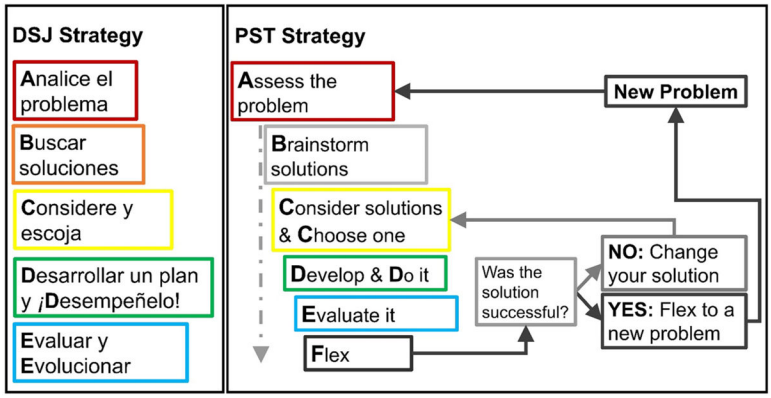

Fig. 2.
Steps of Problem-Solving Training (PST) and Descubriendo Soluciones Juntos (DSJ).

Table 1

PST/DSJ intervention protocol.

3 Session	6 Session	Content
Session Number		
1	**1**	**PST/DSJ Overview:** Introductions and overview of the process; Rapport building; Teach PST steps (ABCDEF) or DSJ steps (ABCDE) and PST/DSJ Worksheets.
	2	**Problem-generation and selection:** Generate potential problems and goals. Select the first problem/goal to address. Using the PST/DSJ worksheet, apply PST/DSJ steps to the first selected problem/goal (ABC). Determine steps to complete prior to next session (D).
2–3	**3–5**	**Apply the PST/DSJ steps to selected problems/goals (iterative practice of the global problem-solving strategy):** Review and evaluate previous plan of action (E) for first problem/goal; Change plan/choose a new problem/goal as appropriate (F in PST; E in DSJ). Continue iterative application of PST/DSJ steps across sessions.
3	**6**	**Review progress and discussion generalization**: Review the problems/goals addressed to date and the progress made. Discuss how to generalize PST/DSJ to daily life, including anticipated problems/goals that may arise in the future.
Between Sessions		**Put plans into action (D):** Try plans developed during sessions to address selected problems/goals. Review success at the beginning of each session using Goal Attainment Scaling. [47] Discuss noncompliance and modify plans to improve compliance.
Booster Sessions		Review PST/DSJ strategy steps and use since the last session, discuss opportunities for applying the strategy to future problems/goals.

Table 2

Inclusion/Exclusion Criteria.

Inclusion Criteria	**Rationale**
Identified as caregiver	Individual (spouse, partner, family member, friend, or neighbor) involved in assisting the person with dementia's with activities of daily living and/or medical tasks or responsible in any way for the person with dementia's well-being.
≥ 1-year relationship	Caregivers must have a pre-existing relationship with the person with dementia.
Ability to communicate in English or Spanish	The PST/DSJ intervention is delivered in English and Spanish and has not yet been translated and adapted to other languages.
≥ 18 years old	A legal adult who could make independent decisions and is developmentally capable of engaging in active problem solving.
Capacity to self-consent	Cognitively able to engage in problem-solving intervention.
Some depressive or caregiver burden symptoms	A score of ≥ 2 on ZBI-4 OR ≥ 2 on PHQ2.
Exclusion Criteria	
Dispute over caregiver's role in care of patient	Such as dispute over the caregiver's ability to participate in the care of the individual with ADRD

Table 3

Outcome measures validated in English and Spanish.

Primary Outcomes	
PHQ [a]	Patient Health Questionnaire (PHQ) assesses DSIM-IV-TR symptoms that define major depressive episode. Scores range from 0 to 27 for severity: 0–4 (none), 5–9 (mild), 10–14 (moderate), 15–19 (moderately severe), and > 20 (severe), and the PHQ has been validated in both English and Spanish speakers [90–93].
ZBI [a]	Zarit Burden Interview (ZBI) is a 22-item self-reported measure of perceived caregiver burden, including items related to psychological and emotional health, well-being, social and family life, finances, and perceive control. Cutoff scores are mild: 2–20; mild to moderate: 21–40; moderate to severe:41–60; severe: 61–88 burden, and the ZBI has been validated in both English and Spanish speakers [94,95].
Secondary Outcomes	
CSQ-8 [a]	Client Satisfaction Questionnaire (CSQ-8) is an 8-item measure of an individual's satisfaction with health-related services they have received, yielding a single summed score (ranging from 8 to 32) measuring overall satisfaction, and the CSQ has been validated in both English and Spanish speakers [96,97].
PAC [b]	Positive Aspects of Caregiving scale (PAC) is a 9-item measure with items rated on a 5-point agreement scale. Two subscales – Self Affirmation and Outlook on Life – demonstrate strong internal consistency (α = 0.86 and 80) [98].
FCS [b]	The Family Caregiving Scale (or Caregiving Experience Scale) measures multiple dimensions listed below. Higher scores indicate more of that particular dimension/scale. • Emotional well-being and physical health • Scales: Life Satisfaction, Social Support, and Carer Overload (scores from 6 to 20, 7–35, and 3–15, respectively). • Caring Role • Scales: Satisfaction, Resentment, and Anger (scores from 6 to 30, 5–25, and 4–20, respectively). • Behavioral Problems Scales: Aggressive, Depressive, and Forgetfulness/confusion (scores from 9 to 36, 4–16, and 5–20, respectively). Refers to care recipient behaviors. • Help provided by recipient Scales: Personal ADL/Instrumental ADL (scores from 0 to 7 and 0–4, respectively). • Help provided by carer Scales: Personal ADL/Instrumental ADL (scores from 0 to 7 and 0–4, respectively). • Family environment Scales: Closeness/Conflict (scores from 3 to 9 and 3–9, respectively).
U-SIRS-13 [b]	The Upstream Social Interaction Risk Scale (U-SIRS) is a 13-item scale that measures an individuals' feelings of disconnectedness, which encompasses aspects of social isolation and loneliness. The U-SIRS-13 yields a single summed score measuring overall risk of being disconnected. Higher scores indicate higher risk [99].
SPSI-R:S Scale [b]	The Social Problem Solving Inventory – Revised: Short Form (SPSI-RS) is a self-report 25-item instrument that measures people's ability to resolve problems in everyday living. It consists of five scales: NPO—negative problem orientation, PPO—positive problem orientation, RPS—rational problem solving, ICS—impulsivity/ carelessness style, AS—avoidance style. Higher scores on each factor denote greater intensity on a particular dimension [100].

[a] Measure was previously validated in Spanish.

[b] Measure was translated to Spanish by our team.